## **Egg donation in the UK, Belgium and Spain: an interdisciplinary study**

**Information about the research**

We would like to invite you to take part in a research project. Before you decide, we want to tell you what we would like you to do and why we are doing the study. Please read this leaflet and ask any questions you may have.

### What is the study about?

This study is exploring how egg donation is organised in the UK, Belgium and Spain, and the experiences of women who provide eggs for use in fertility treatment as well as those of the clinicians and other professionals who provide their care. We are also interviewing a number of policy and practice stakeholders about their views.

### Why have I been chosen?

You have been asked to take part because you have provided your eggs for use in fertility treatment **in the UK [or insert country] since 1st April 2012** through egg donation, egg sharing, a freeze and share programme or you applied to donate or share your eggs but did not complete a cycle for any reason.

### What does the study involve?

Participation in the study will be through a research interview. A research interview is a conversation between you and the researcher, where the researcher will ask you to talk about your opinions and experiences of egg provision in the UK. The interview will last around one hour and be conducted at a time and place that suits you. Just you and the interviewer would be present and the interview would be audio-recorded. A telephone/Skype could be arranged if this is preferable. We cannot pay you for your time but will offer you a £25 gift voucher to say thank you for your participation.

**What are the possible disadvantages and risks of taking part?**

You will need to allow enough time for the interview to take place. Due to the nature of the study, the interviews will cover potentially sensitive and emotional topics. If there are any topics you do not wish to discuss, just tell your interviewer and we will move onto another question. If you become upset at any time during the interview we can take a break or stop the interview according to your wishes. You will have the opportunity for post-interview questions. If you would like further independent information following the interview you may wish to contact organisations such as the National Donation Trust ([ngdt.co.uk](http://www.ngdt.co.uk)), British Infertility Counselling Association (bica.net) or the Human Fertilisation Fertilisation and Embryology Authority (hfea.gov.uk).

**What are the possible benefits of taking part?**

We aim to gain a better understanding of how egg donation is organised, practiced and experienced in the UK, Belgium and Spain and to make recommendations for a range of stakeholders to develop policy recommendations to improve care and support for women who provide their eggs for use in fertility treatment.

**What will happen to the data?**

The interview recordings will be typed up verbatim and the electronic recordings and typed up files (transcripts) will be kept on password-protected PCs in the UK. Any printed documents will be kept in a locked filing cabinet. Transcripts will be anonymised; any information that could identify you (e.g. your name, where you work) will be removed. At the end of the study, audio files will be destroyed and anonymised transcripts will be stored for 15 years. As this study and others like it is paid for from public funds, the funding body (the Economic and Social Research Council in the UK) has developed ways to share data among academic researchers (subject to strict conditions). To this end, we plan to store short English language descriptive summaries of the interviews from the study with the UK Data Archive (a service provider for the Economic and Social Data Service) to help other researchers looking at egg donation. If you do not wish us to do this with your data you can still take part in the study; just place an “x” in the final box on the consent form.

**What will happen to my personal details?**

Your personal details will be kept on password-protected PCs in the UK so that we can contact you during the study. Once the study has finished, we would like to keep your contact details for one year so that we can tell you about our findings and about future research we may carry out. If you do not want us to do this, please place an “x” in the appropriate box on the consent form and your personal details will be destroyed at the end of the study.

**Will my taking part be kept private?**

Yes, your details will be kept confidential and any information relating to you will be anonymised or removed.

**Who will have access to my data?**

The research team will have access to your recording and transcripts. If you agree to English language descriptive summaries (see above) of the interviews being held at the UK data archive, other researchers may request permission to access these via the archive, under strict conditions. However, this will be anonymised and nobody will be able to identify you.

**How will my data be used?**

We want to find out more about women’s experiences of egg donation and aim to develop policy recommendations to improve care and support for women who provide their eggs. To do this, we are working in partnership with the National Gamete Donation Trust in the UK. We would like to share our findings with other researchers, academics and policy advisors through academic journal publications and conference papers. We would also like to publicise our research to a wider non-academic audience through public lectures, exhibitions and the media.

**What will happen to the results of the research study?**

There will be a summary of the findings from the study available at the end of the project and you can receive a copy of this if you wish. We will also publish the findings in academic journals and at academic conferences, but all information about participants will be anonymised.

**Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part and then change your mind you can withdraw up to 7 days after the interview. Please tell us if you change your mind by contacting Christina at [christina.weis@dmu.ac.uk](mailto:christina.weis@dmu.ac.uk) or on 0116 250 6576.

**What if something goes wrong? / Who can I complain to?**

If you have a concern about any aspect of this study you should speak to the lead researcher, Prof. Nicky Hudson, she will do her best to answer your questions. If you would like to speak to someone outside of the research team, please contact the chair of the Research Ethics Committee at De Montfort University, Professor Martin Grootveld, tel: +44 (0)116 250 6443, e-mail: [mgrootveld@dmu.ac.uk](mailto:mgrootveld@dmu.ac.uk).

### Who is organising and funding the research?

The research team are**:** Professor Nicky Hudson (lead researcher), Professor Lorraine Culley, Dr Cathy Herbrand, Dr Katie Coveney and Dr Christina Weis (De Montfort University); Professor Guido Pennings and Professor Veerle Provoost (Ghent University), and Dr Vincenzo Pavone and Dr Sara Lafuente (Consejo Superior de Investigaciones Científicas). It is funded by the Economic and Social Research Council (ESRC), grant ref ES/N010604/1. The ESRC is the UK’s largest public funding body and fund research on social and economic issues. For more information please go to [www.esrc.ac.uk](http://www.esrc.ac.uk)

### Who has reviewed the study?

This study has been reviewed and approved by De Montfort University, Faculty of Health and Life Sciences Research Ethics Committee.

### Contact for Further Information: Dr Christina Weis, Centre for Reproduction Research, Hawthorn Building, The Gateway, De Montfort University, Leicester LE1 9BH. E-mail: christina.weis@dmu.ac.uk, Tel. 0116 250 6576. You will be given a copy of this information sheet and a copy of the signed consent form to keep.

**Thank you for reading this information.**